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Review Article

What Works to Improve and Manage Fecal Incontinence in Care Home Residents Living With Dementia? A Realist Synthesis of the Evidence



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ABSTRACT

Keywords:

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constipation

The prevalence of fecal incontinence (FI) in care homes is estimated to range from 30% to 50%. There is limited evidence of what is effective in the reduction and management of FI in care homes. Using realist synthesis, 6 potential program theories of what should work were identified. These addressed clinician-led support, assessment, and review; the contribution of teaching and support for care home staff on how to reduce and manage FI; addressing the causes and prevention of constipation; how cognitive and physical capacity of the resident affects outcomes; how the potential for recovery, reduction, and management of FI is understood by those involved; and how the care of people living with dementia and FI is integral to the work patterns of the care home and its staff. Dementia was a known risk factor for fecal incontinence (FI), but how it affected uptake of different interventions or the dementia specific continence and toileting skills staff require, were not addressed in the literature. There was a lack of dementia-specific evidence on continence aids. Most care home residents with FI will be doubly incontinent; there is, therefore, limited value in focusing solely on FI or single causes, such as constipation. Medical and nursing support for continence care is an important resource, but it is unhelpful to create a distinction between what is continence care and what is personal or intimate care. Prompted toileting is an approach that may be particularly beneficial for some residents. Valuing the intimate and personal care work unqualified and junior staff provide to people living with dementia and reinforcement of good practice in ways that are meaningful to this workforce are important clinician-led activities. Providing dementia-sensitive continence care within the daily work routines of care homes is key to helping to reduce and manage FI for this population.

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Fecal Incontinence in Care Home Residents Living With Dementia

Approximately 80% of residents in nursing or care homes have dementia or memory problems,^{1–6} and the prevalence of FI is estimated to range from 30% to 50%.^{1–3,6–8} Dementia is an independent risk factor for FI.^{2,9,10} FI is defined as the involuntary loss of liquid or solid stool that is a social or personal hygiene problem.¹¹ FI is distressing, humiliating, and potentially stigmatizing for any adult. Managing another adult's excrement is outside the usual expectations, and can engender emotions of disgust and distaste.¹²

Current evidence about FI in people in long-term care settings is mixed, with some good evidence on risk factors,^{1,13} the impact of comorbidity,¹⁴ and the impact of different organizational contexts.^{3,9,10} There are few intervention studies and little conclusive evidence of what is effective management of FI in people resident in care homes.^{15,16} Care homes are the main providers of long-term care for older people in many developed countries and accommodate those who require help with personal care and are unable to be supported in their own home due to medical, functional, or mental health problems. They include settings that have on-site nursing provision and those that do not. They are often administered by a nonclinical manager in many countries. This article reports the main findings of a realist review and synthesis of evidence for the management of FI in older people with dementia in care homes.¹⁷ The definition of care homes includes nursing homes, residential homes, aged long-term care, assisted living facilities, and dual-registered homes.

The objectives of the review were to

1. Identify which interventions to reduce and manage FI could potentially be effective, how they might work, on what range of outcomes (ie, organizational, resource use, and patient level of care), and for whom (or why they do not work)
2. Establish evidence on the relative feasibility and cost of interventions to manage FI

Realist Review

Realist review is a theory-driven approach to reviewing a range of published and unpublished literature, whereby evidence is assessed and used based on its relevance in terms of contributing to (and testing and refining) an emerging understanding about the different aspects of an intervention and how it may work.^{18–20} Interventions to reduce and manage FI in care homes are always complex and their outcomes are context-dependent. Realist approaches emphasize understanding causation in terms of how interventions generate outcomes through the medium of human decisions and reactions that are themselves affected by social context.^{18,20} The often-repeated statement used to explain realist review is that it makes explicit “what works, for whom, in what circumstances?” The focus on causal mechanisms and necessary conditions for success ensures rigor, even when contributing evidence may be of variable quality.

Methods

The review had 3 linked phases: an initial scoping of the evidence to refine the question and build potential midrange theories about what determines “good” care in the reduction and management of FI (scoping searches and stakeholder interviews); an in-depth review phase to test and refine the proposed theory areas (continuous literature searching, retrieval, inclusion/exclusion, data extraction, review, and appraisal); and a final testing, refining, and validation phase (theory testing, refining, and stakeholder review). Further details are available in the protocol²¹ and final report of the review.¹⁷ Ethics approval was obtained

via the University of Hertfordshire ethics committee: University of Hertfordshire protocol reference HSK/SF/UH00088.

Review methods and reporting for the realist synthesis followed the RAMESES (Realist And Meta-narrative Evidence Syntheses: Evolving Standards) guidelines.²⁰ An iterative approach was used to define the scope of the review and identify potential candidate theories for testing in the literature. Context–Mechanism–Outcome configurations (CMOs) were used as a tool to understand what is going on in interventions. This does more than describe barriers and enablers, it theorizes how interactions among the environment, the people, and the resources may result in different patterns of outcomes. We asked, “what does good continence care looks like?” and used multiple sources of evidence within key contexts (C) and we hypothesized mechanisms (M) of interventions to explain the outcomes (O) (see [Box 1](#)). We tested the CMOs against the relevant evidence to build context-sensitive theory providing causal explanations for different settings, situations, and participants of what supported the reduction and management of FI for residents in care homes when and with what outcomes. Published and unpublished evidence was systematically searched and used to test possible CMOs within and across the evidence reviewed. Four separate searches were undertaken in phase 1, and in phase 2 these were expanded and refined (see [Boxes 2 and 3](#)). All strategies are available on request and available in the full report.¹⁷ Databases searched included PubMed, CINAHL, The Cochrane Library, Scopus, SocAbs, ASSIA, BiblioMap, Sirius, OpenGrey, Social Care online, and the National Research Register without date restrictions up to March 2015.

Five stakeholder group interviews were conducted with a purposively selected sample of care home managers, care home staff, service user representatives, practice educators, academics, clinicians (ie, doctors, nurses, and allied health professionals) with specialist interest in FI, continence specialists, and commissioners and providers of continence services ($n = 44$), as well as incorporating our own prior knowledge of this field. Interviews were used to explore assumptions and theories of what was important for the effective care of people living with FI and dementia. Interviews were recorded, transcribed, categorized thematically, and analyzed on how different participants described what good continence care looked like, what needed to be in place to achieve it, and how effectiveness could be measured. Field notes also were taken to capture *how* participants discussed different issues within the group, where there appeared to be uncertainty and consensus. Data from the scoping searches and interviews were used to develop narratives, tables, and summary diagrams that captured

Box 1. Definitions of realist terms and how they have been applied throughout the review

- Context (C): Context can be broadly understood as any condition that triggers and/or modifies a mechanism; the background situation, for example, clinical assessment, provision of training, resident's diet and hydration, or cost of continence aids.
- Mechanism (M): A mechanism is the generative force that leads to outcomes. It may denote an action or reasoning of the various “actors” (ie, care home staff, residents, relatives, and health care professionals). Identifying the mechanisms goes beyond describing “what happened” to theorizing “why it happened, for whom, and under what circumstances.”
- Outcomes (O): Intervention outcomes; for example, reduction in episodes of FI, reduction in resident distress, family caregiver satisfaction with care, staff confidence, costs. An outcome of one CMO configuration may be the context of another CMO configuration.

Box 2. Literature searching: Scoping search areas

Scoping searches

1. Continence-related research in care homes, dementia and continence, older people and continence, implementation research in care homes, and person-centered dementia care
2. Fecal incontinence, care homes, and incontinence pads
3. Literature on interventions to promote nutrition and hydration (eating and drinking) for PLWD in care homes. This was to test whether this body of work included outcomes related to continence and FI
4. Scope the learning disability (intellectual difficulty) literature for continence-related research
5. All types of evidence, including empirical studies on FI, policy documents, staff guidance, book chapters, and theses

Databases searched: PubMed and Cochrane Library.

multiple areas of what needs to be in place to achieve improved resident outcomes for FI (eg, continence, dependent continence, appropriate use of pads, comfort, personalized care, minimization of distress, skin integrity). This made explicit the interactions among the environment, people, and resources that may result in different CMO configurations and outcome patterns.

Searches retrieved 1500 potentially relevant sources: empirical studies, policy and staff guidance documents, book chapters, and theses. A total of 287 sources were examined during the project, and we systematically extracted data from 62 core articles selected based on their relevance to the developing theories. Agreement was reached by consensus within the team. Bespoke data extraction forms were populated by all members of the project team with all articles read independently by at least 2 people. Data were extracted on type of literature (eg, intervention study, observational study, policy document), country, setting, methods, study outcomes, and which theory areas they related to. Quality assessments were completed for the 8 intervention studies using a modified version of the Cochrane risk of bias tool.²²

Data extraction captured the evidence on CMO configurations of different theories and patterns that were supported or negated. The emergent propositions of what supports effective care for people living in care homes with dementia and FI were tested, refined, and validated by discussing findings and implications for future research

Box 3. Second literature-search areas

Searches 1a and 1b searched for evidence on care home research, continence, or FI, which included PLWD, and care home research covering implementation or patient-centred care (PCC) that included people with dementia. Search 2: Continence literature in care homes that may be about factors associated with FI, such as the use of incontinence pads or constipation.

Search 3: Research in care homes for people with dementia that concerned nutrition and or hydration in the care home population. We were interested in outcomes relevant to FI or urinary continence as well as learning on implementation.

Search 4: Literature on continence care for people with learning disability.

Databases searched: MEDLINE, EMBASE, CINAHL, PsychINFO, The Cochrane Library, Joanna Briggs.

and practice among the project team and with a purposive sample of stakeholders (from phase 1).

Results

Six broad theory areas were identified that could explain how to improve continence care for people living with dementia and FI in care homes. These were as follows: (1) Clinician-led support, assessment, and review; (2) ongoing teaching, review, and feedback to care staff on how to reduce and manage FI; (3) addressing the causes and prevention of constipation; (4) interventions that reflect the degree of cognitive and physical capacity of the resident; (5) common understanding of the potential for recovery and reduction of FI; and (6) integrating care for people living with dementia and FI into everyday work patterns of the care home and staff. The key findings from group interviews and evidence for the different CMOs are presented.

Stakeholder Group Interviews and Literature Scoping

Although all stakeholders highlighted how distressing FI could be for both residents and staff and how important it was to know the resident, there were differences in emphasis among different groups. For example, doctors focused on the issues such as “regular assessment” and nutrition and hydration, whereas direct carers and family focused on approaches that stressed knowing the resident’s biography, and that promoted empathy and clarity/leadership within the care home. These findings were summarized by stakeholder groups’ accounts of what is effective as possible CMO configurations. The detailed tables are available in the full report.¹⁷

Evidence from the scoping review was summarized in 4 broad narratives:

- (1) A cumulative program of work in continence research in nursing homes in the United States by Ouslander et al and Schnelle et al^{23–37} demonstrated how interventions have been progressively refined over time, with an increasing emphasis on the involvement of care home staff in training and structured programs of prompted voiding. There was, however, a lack of evidence or guidance about how to implement these approaches in settings with limited access to doctors or how a person’s dementia will have an impact on implementation.
- (2) A wider care home literature on what needs to be in place when introducing new interventions to improve care for people with dementia in care homes that were predicated on person-centered approaches. This included interventions such as person-centered care, medicine management, therapy interventions,^{38,39} and nonpharmacological approaches to the reduction and management of behavioral and psychological symptoms of dementia.^{40–46} The relevant learning from these studies was that training, learning, mentoring, and posttraining support are important, but do not of themselves lead to staff engagement and motivation to change practice or care routines.
- (3) Guidance and review articles relevant to the management of FI in older people living in care homes/long-term care.^{47–58} This work emphasized the importance of assessment, nutrition, hydration, and the diagnosis of fecal impaction. The underlying narrative being that clinical assessment was essential, but how this was achieved lacked detail, particularly in care home settings for people living with dementia. The scoping highlighted a gap in the research between studies focused on solely dementia care and those focused solely on continence care. This gap is picked up later in the article whereby we assess how included continence studies measured and considered dementia.

Table 1
Description of Evidence Sources by Broad Research Themes

Evidence on continence care (but not FI specifically) and dementia in a care home setting: 3 sources^{67–69}

Two intervention studies from the 1990s about environmental effects on incontinence problems in patients with Alzheimer disease living in a specialist care facility and a book for direct care staff of people with dementia resident in care homes with a section specifically addressing continence care.

Evidence on UI in a care home setting, but not dementia or FI: 21 sources^{8,15,26,29,30,70–85}

Sources from 1989–2015. Eight intervention studies (1 randomized controlled trial [RCT]), 9 observational, 4 qualitative interview studies, and a review.

Evidence on FI and/or bowel health (also covering constipation) in a care home setting, but not dementia: 15 sources^{10,23,25,33,50,86–95}

Sources from 1986–2015 focusing on FI, bowel problems (including constipation), and diarrhea in care homes. Five intervention studies (1 RCT), 7 observational studies, and 3 reviews.

Evidence from interventions specifically for people with dementia, but not continence interventions, in care home settings: 12 sources^{41,44,96–105}

Sources from 2003–2015 covering psychosocial interventions, morning care, bathing, eating and drinking, and PCC interventions. Seven intervention studies (3 cluster RCTs and 1 RCT), 4 reviews, and an observational study.

Evidence on “implementation” of interventions in a care home setting: 7 sources^{43,106–112}

Sources from 2000–2015 covering implementation in care home settings, 3 intervention studies, 2 observational studies, 1 review, and 1 book (2 chapters).

Evidence from specific novel interventions to manage continence/bowel health in a care home context: 4 sources^{113–116}

Studies from 2000–2013 that address residents in care homes with dementia or make reference to the application to the person with dementia. Four intervention studies (1 RCT).

(4) Absorbent products for FI. Although extensively used in care homes for the management of FI, we found very few studies that have compared the different designs of absorbent products.^{59–64} The emphasis has been mainly on testing pads with patients with urinary incontinence (UI), and the studies did not consider how dementia affects the person's use of continence aids nor their use for FI.

Outcomes

From the stakeholder interviews and across the different types of literature, the reduction of distress and improvement in symptoms were important measures of effectiveness, but there was little consensus on what might be other important outcomes (see [Appendix 1](#)). Cost-related outcomes in particular are not well defined or measured.

Clarifying Definitions of FI and Dementia

The scoping identified the need for a more dementia-focused definition of FI that sees it as an aspect of “toileting difficulties” that may be experienced by people living with dementia. Toileting difficulties are the “voiding of urine or feces either following an unsuccessful effort or with no apparent attempt to use an acceptable facility.”⁶⁵ This conceptualization reframes continence in the social and environmental context. How the original definition of “involuntary loss” translates to people with dementia and FI in studies is unclear, with the frequency of FI episodes classed as constituting FI differing between studies. FI in this broader definition is recognized as having multiple causes that may include constipation; cortical atrophy; neuropsychological, sensory, or physical disability (mobility and dexterity); medication effects (sedatives, antidepressants, diuretics); or psychological factors (personality, habits, life experience, and mood). All of these causes are further compounded by the care home design, including distance to the toilets, obstacles, visual access, signage, and the actions and attitudes of others.

The original review brief was to look at *advanced* dementia; however, the lack of continence studies addressing dementia, and inconsistency in how dementia is assessed and recorded for care home residents, coupled with the lack of consensus as to how to define “advanced dementia” in relation to continence care, meant that the distinction between dementia and advanced dementia was not useful. Moreover, as FI in care home residents is almost always associated

with UI,⁶⁶ there was limited value in focusing solely on FI in people living with dementia (PLWD) and so UI evidence was also considered.

Theory Testing

The 6 theory areas were tested with the evidence from the 62 included sources. The detailed data extraction forms noted for which theory area(s) the source had relevant evidence (confirming or disconfirming), and multiple CMO configurations specific to the source. [Table 1](#) gives an overview of the type of evidence by broad research themes and shows the diversity of evidence used. We now present the evidence by theory area.

Theory 1: Clinician-led Support, Assessment, and Review Will Achieve Observable Improvements in FI

This area reflects the assumptions and training of clinicians. Twenty-one sources were relevant to this area.^{8,30,37,41,50,67,70,86–90,96,97,106–109,113,117,118} Evidence suggested that when clinicians (specifically geriatricians) apportion time and energy to working with care homes, they can drive improvements in the prevention and management of FI. However, studies did not specify exactly what the clinicians' role entailed, nor was it clear if the improved outcomes applied to PLWD or if having dementia affected someone's ability to benefit. This approach is much influenced by the seminal study of Tobin and Brocklehurst,⁸⁶ which concluded that most FI was due to fecal impaction and could be resolved with “simple measures.” However, a study 20 years on by Akpan et al⁸⁸ found that FI was not resolved in their sample of nursing home patients and suggested that either the original study does not apply to current nursing home populations (who are now significantly older, with more comorbidities and severe cognitive impairment) or findings are not being implemented, or both.

Review and guidance literature (that was summarized in the scoping review) note the high prevalence of FI in physically and cognitively impaired patients and describes available physical examination and diagnostic tests. Details on how to take a history and complete examinations in PLWD are not provided. Difficulties achieving the ideal level of investigation and assessment, especially in long-term care facilities, were noted. Current literature does not address the complexity of delivering interventions for PLWD who have FI.

Theory 2: Ongoing Teaching, Review, and Feedback to Staff on Assessment and How to Reduce and Manage FI

The importance of clinician assessment is linked to the assumption that giving staff access to the appropriate training, education, and facilitation will result in a change in practice. This area is important to consider, as so many care home interventions use a training, education, or facilitation approach. Sixteen sources were relevant to this area, with some detailed accounts of implementing interventions through training and education.^{29,30,41,71–75,91,92,96–100,106}

Two articles reporting the use of distance coaching and coursework in US nursing homes^{29,30} found qualified support for using this approach to encourage staff (mostly nurses) to implement prompted voiding. One-third of nursing homes dropped out of the program; however, for those completing the courses, there was improvement in knowledge (average pretest to posttest score improvement, independent *t* test): course 1 participants (*n* = 15) 57% to 73% (*P* = .01) and course 2 (*n* = 35) participants 57% to 85% (*P* < .001). Although the authors discuss issues around feasibility of implementing this approach and clearly recorded and calculated costs of the training intervention, there was insufficient detail provided to understand which elements of the training were working for particular nursing homes or staff groups. Lack of “time to do training” was cited as a barrier, even though webinar timings were adapted to suit course participants. The wider care home literature^{41,43,44,100} highlighted similar issues around “substantial time commitment” required for training and mentoring. Results from a qualitative study on the implementation of psychosocial interventions in care homes to reduce antipsychotic prescribing⁴³ suggest that, although knowledge, skills, and time may be important contextual factors for implementing interventions in care homes, a key mechanism comes from activities that foster the development of a shared understanding of the problem and an enhanced status of the work. The following is an example CMO from this study: a training program (to reduce antipsychotic drug use in care homes) was delivered to all staff AND family members (C). This program triggered a shared understanding about behaviors staff find challenging and the approaches that can be used to improve these (M) with the outcome (O) that staff groups and family work together to provide care to the resident and reduce the use of antipsychotic drugs.

Evidence suggests that offering more training for care staff on FI with structured guidelines and facilitation will not lead to better management or reduction of FI if it does not account for key contexts, such as the work pressures of the care home or consider if staff have the autonomy to act. A recent study⁹¹ testing the hypothesis “that fecal incontinence can be prevented, cured, or ameliorated by offering care staff knowledge of best practice” had difficulty recruiting nursing homes and found changes in the rates of FI were not sustained. It was concluded “For the main study, empowering RNs [Registered Nurses] in the nursing role and helping them find ways to best organize the work on their own unit and give feedback to the rest of the care staff will be important.” Analyzing evidence shows how contexts can be linked to outcomes by theorizing potential mechanisms. Training interventions may be successful or unsuccessful depending on context and complex interactions of culture and practice.

Theory 3: Knowledge on Causes, Management, and Prevention of Constipation for Older People with Dementia

A commonly held belief, supported with early empirical work,¹¹⁹ is that successful management of constipation could lead to a reduction in FI for older people in institutionalized care. This theory area overlaps with Theory 1 (clinician-led support and review). The key difference is that a focus on management of constipation as a significant contributory factor of FI will lead to overall improvement in FI.

Sixteen sources provided relevant evidence.^{8,10,23,25,33,50,75,89,92–94,107–109,113,114} A 1996 study²³ found that prompted voiding had increased continent bowel movements. They suggested the increase in physical activity and fluid intake resolved fecal impaction. Ten years later, the same team warned, however, that overuse of laxatives as prophylactic treatment for constipation can result in FI.²⁵ Other studies^{70,92} found reduction in laxative-induced FI did not arise due to better understanding of causes of constipation but from change in care home practice to routinely dispensing laxatives that had been prescribed pro re nata (PRN). More recent work by Saga et al.^{93,94} found that a preoccupation of nursing staff with constipation and a person's bowel being empty meant care home staff accepted FI and used pads to cope with the consequences. Evidence suggests that although knowledge of constipation and its causes is important, there could be unintended consequences, such as overuse of laxatives and acceptance of use of pads.

Theory 4: Interventions that Reflect the Degree of Cognitive and Physical Capacity of a Resident: Personalized Care Planning

This theory area encapsulates the patient-centered care (PCC) approach that values individualization, empathic understanding, and creating relationships to provide for psychological needs: comfort, identity, inclusion, attachment, and occupation, thereby promoting well-being and minimizing distress for PLWD. In this framing, FI or its treatment is an aspect of health that may affect the toileting difficulties people can experience.⁶⁵

Thirty-one sources had evidence relevant to this area.^{23,25,33,41,43,44,50,67,68,75–79,87,92–104,109,110,115} Evidence suggested managerial support and endorsement were needed to embed PCC within a care home.⁹⁹ There was not, however, a shared understanding of what PCC involves in care home settings.⁹⁹ Lawrence et al.⁴³ found that a person-centered working style, and focus on residents as individuals with differing needs and preferences, could develop in settings in which staff were encouraged to form bonds with residents rather than taking a task-oriented approach. Studies that addressed the dementia-specific issues of providing personal and intimate care to care home residents^{98,104} offer transferable learning about what needs to be in place to reduce distress and minimize resistance to care. This work showed promise, but noted that “organizational factors”¹⁰⁴ and “facility-wide culture change”⁹⁸ were important for implementation. One Australian study⁷⁷ illustrated the tension that care home staff may experience when asked to implement PCC if, for example, the need for residents to appear clean and well-groomed was given priority over individualized approaches to care, such as prompted toileting.⁷⁸ To achieve outcomes, such as reduced resident distress, using a more reflective personalized approach requires both empathy and permission for staff to work in this way.³⁴

Of 43 studies that addressed continence care in some form, only 20 included PLWD; of those, only 16 assessed the severity of the dementia (a detailed summary of these 20 studies can be found in the full report).¹⁷ It is striking that, apart from the acknowledgment that dementia is a risk factor for FI and that this increases with immobility, only 3 sources specifically address dementia behaviors and FI within an intervention. Two studies conducted in the early 1990s in an Alzheimer disease unit focused on improving environmental clues (signage and removing the visual barrier to the toilet in patient's rooms). The studies provided some evidence that appropriate visual cues can encourage toilet visits for older PLWD in aged care facilities, but this may not translate to appropriate toilet use.^{68,69} The third source is a practice tool for direct care staff of people with dementia resident in care homes with a section specifically addressing continence care, including pictures of how best to help people use the toilet. Examples include how to communicate nonverbally or what to do if someone “freezes” and refuses to sit.¹²⁰

Theory 5: Establish a Common Understanding of the Potential for Recovery, Reduction, and Management of FI for People with Dementia

This theory area posits that it is what staff believe about the potential for improvement or reduction in episodes of FI that determines the kind of continence care a person with dementia may receive.

Twenty-two sources contributed to this theory area.^{8,33,43,50,67,72,74,77,79,80,86,92–94,96,98,100,104,106,108,110,121} All were also associated with the theory areas around clinician-led assessment and review, ongoing teaching, review and feedback, and PCC approaches. In one multicomponent prompted voiding study in a care home,³³ people with cognitive impairment responded particularly well to the intervention. This suggests older PLWD can benefit from toileting assistance and prompting. A study in Norwegian nursing homes found that some staff have negative perceptions about the possibility of improving FI in PLWD, and felt that it was not worth pursuing interventions other than pads.⁹⁴ This suggests that a lack of shared understanding around the potential for reduction of FI is an important context that triggers a resistance in staff uptake of learning in FI care; thus, should be acknowledged and addressed in interventions, but may not be the key factor.

Theory 6: Integral to the Everyday Work Pattern and Environment, “Fit”

Recurring narratives from the care home research reviewed under the other theory areas underlined the need for new approaches to care to fit within existing structures of authority and working practices in the care home. Forty-one sources were relevant to this theory area.^{8,26,29,30,41,43,44,68–83,87,88,90,92,96,99,100,103,104,107–112,115,122,123} Burzio and Engel and colleagues^{71,72} investigating behavioral treatments for UI and FI (in the 1990s) concluded “the only two mechanisms by which toileting programs are likely to succeed: one is by increasing the number of trained personnel and the other is by redistributing staff time....”⁷² This indicates this theory is not new but has not been previously explored with particular reference to residents who are living with dementia or how continence-related care is framed in the day-to-day work of care home staff. For staff to believe that change is possible, enough time, encouragement, and support are required.

How the “fit” with working practices was expressed ranged from whether the intervention was embedded in team working, related to normal working practices of staff, and if staffs’ continence work was embedded in their daily work. Rovner and colleagues¹²³ identified physicians completing documentation, and being involved in ongoing discussion with staff, as the potential reason their intervention was sustained (for 9 months after the end of the study period). The intervention was a work priority for all staff and ongoing involvement of the clinician endorsed the activity.

Saga and colleagues⁹⁴ noted that a resident’s need for assistance was a trigger or “protective” factor for FI, with staff being more proactive in supporting the achievement of dependent continence in patients who needed help transferring from a bed to a chair.

An Australian study on continence care in care homes depicted continence care as “caring against the odds” and was characterized by 4 major subcategories: (1) working in a highly regulated work environment; (2) encountering ethically challenging situations; (3) highly dependent residents; and (4) a devalued role.⁷⁷ P⁵ This analysis goes beyond earlier statements about needing time and demonstrates that an important context is whether the intervention explicitly addresses care home-specific patterns of working.

Discussion

Dementia is a risk factor for FI, and in care home residents is almost always present in conjunction with UI. The testing of different program theories of what needs to be in place to reduce or manage FI established that solely focusing on resolving constipation can exacerbate FI. It also demonstrated the importance of making the link between continence care and intimate care of PLWD. Continence care is delivered by the lowest-paid frontline care staff in care homes. Understanding how their contribution affects uptake of practices that are likely to be beneficial (for example, assessment, working with clinicians, regular toileting) is key. The review highlighted 2 areas of dissonance in how research on FI has been undertaken. First, a limited engagement in the research with how living with dementia affects a person’s ability to benefit from continence-led interventions and second, a mismatch between what researchers consider achievable, and the real world of direct care delivery.

How the dementia trajectory affects a person’s ability to benefit from different interventions for FI is unknown. Few studies have compared different designs of absorbent products for FI or the particular needs of people with dementia in care homes. Clinical, educational, and PCC approaches may be uncontentious. Constipation should never be ignored, but may not be as important an etiology as the use of laxatives in long-term care settings. Activities such as clinical assessment and a focus on PCC need to support the development of a “common understanding” among clinicians, staff, families, and residents. Use of the evidence of what reduces and manages FI needs to both fit with working practices of the care home, and recognize the dementia care skills that the least-qualified staff might need.

Strengths and Weaknesses

A strength of this synthesis is that it provides a comprehensive account of what influences, supports, and inhibits practices that can promote better reduction and management of FI of PLWD in care homes. It developed and tested a theoretical understanding of what supports the reduction and management of FI in long-term care settings. We tested and debated the relevance and resonance of the emergent findings with stakeholders at each stage of the review. From the outset, the paucity of evidence on what is effective was known, but in realist terms, even when the desired outcomes were not achieved, it was possible to learn from the evidence and develop a theoretical understanding of what needs to be in place. The inclusion of a wider literature (eg, around bathing, and reduction of antipsychotic prescribing) that has similar preoccupations and challenges has demonstrated recurring preoccupations around containment that has similar preoccupations and challenges (in this case of behavior), the significance of care home routines on uptake of interventions, and how living with dementia reframes how everyday clinical problems and activities are assessed and addressed. The findings suggest that FI-related interventions that fail to tailor practices to fit with care home working, or do not provide ongoing support to staff on dementia informed continence care will probably have limited impact.

In the validation phase, family carers highlighted that the review did not address the amount of time and resource given to cleaning up after episodes of FI, nor concerns about cross-infection arising from, for example, PLWD engaging in smearing or parcelling of feces. It is a limitation that the evidence was insufficient to address the use of continence aids for FI or relative costs of different management approaches (eg, prompted toileting, use of pads). However, it reinforced the finding that the reduction and management of FI cannot be separated from the everyday work of cleaning and clearing up or residents’ actions that arise from living with dementia.

Conclusions

This review provides an emergent conceptual model that articulates what are likely to be the minimum requirements for continence interventions targeting people living with FI and dementia in care homes. It has done this by setting out the evidence for the different possible CMO configurations that need to be in place and has argued that interventions are more likely to achieve the outcomes of interest when continence care is reframed as integral to intimate and personal care work for older people with dementia. Personal and intimate care requires a set of skills that can ensure care is responsive to the individual resident's preferences and needs. These skills need to be formalized in job descriptions, taught to those who give this care (junior/inexperienced staff), and valued and supported by senior staff. Care home staff across different disciplines and grades need to have the opportunity to reflect on practice and learn from each other about how to promote continence. Where reflective practice is already part of care home practice, continence, FI, intimate and personal care, and dementia care can and should be explicitly linked.

There is good evidence that appropriate diet, fluid intake, and increased mobility help as part of improving FI. The ways in which these strategies are introduced or improved for those residents with dementia should incorporate both the preferences of the person with dementia and consideration of how the activities and routines of the care home support this.

Further research is needed that considers how different care routines and practices can be aligned with interventions to enhance continence care for this population.

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Appendix 1

Resident, Staff, and Organization Outcomes Categorized by Research/Stakeholder Perspective

Resident Outcomes	Staff Outcomes	Organisation Outcomes
Outcomes proposed by stakeholders		
Continence (dependent) Recognition/use of toilet Minimisation of leakage Skin integrity Comfort Minimisation of distress Dignity	Increased knowledge (about continence/dementia) Confidence Work satisfaction Change in attitudes to ageing and dementia	Costs Resource use e.g. continence products and laxatives Use of health services Reputation Workforce turnover
Outcomes from the continence literature		
Frequency Stool weight and presentation Odour Skin integrity and hygiene Behavioural change/symptoms of distress Acceptability of intervention to residents Improved continence	Staff adherence to protocol Staff knowledge Observed change in practice Acceptability of intervention to staff	Resources used : staff time and equipment used
Outcomes from the PCC literature		
Expressed and observed distress in residents QoL and Quality of Care measures Improvement in neuropsychiatric symptoms	Behaviour change of staff Sense of personal accomplishment Evidence of staff leading decision making & increasing confidence Staff knowledge	Culture change
Outcomes from the Care Home Implementation literature		
Acceptability Residents' independence /dignity/choice	Staff engagement/attrition from intervention Change in practice reported/observed Evidence of change in documentation/Recording Acceptability Improved staff knowledge Staff confidence Breadth of staff discussion, engagement & encouragement of leadership team	Costs